

**Maternal and Child Health Improvement Projects
Abstract**

Project Title: Hawaii Genetic Awareness, Implementation, and Data Project
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Project Period: 3 Years **From:** 6/01/2001 to 5/31/2004

Purpose: The Hawaii Genetic Awareness, Implementation and Data (Gene AID) Project will continue to implement its current and revised State Genetics Plans and integrate the information and referral systems for the Newborn Screening programs, Children with Special Health Needs Program and Early Intervention Services program.

Challenges: The project is designed to integrate newborn screening, birth defects and early intervention data systems within the framework of federal and state laws. The project also proposes to increase statewide genetic awareness for a broad audience and implement genetics into public health programs while trying to address consumers with limited science knowledge.

Goals and Objectives: The long term goals and objectives for this project are to:

- 1) Integrate Newborn Metabolic Screening, Newborn Hearing Screening, Children with Special Health Needs, and Early Intervention Services Program data and/or referral systems;
- 2) Increase genetic awareness in physicians, public health professionals, consumers, legislators, and policy makers;
- 3) Incorporate genetics content and follow-up into appropriate public health programs; and
- 4) Help ensure that public health genetics programs have stable and sustainable funding.

Methodology:

- 1) Integrate data and/or referral systems
Data from newborn metabolic screening and newborn hearing screening programs and birth defects program will be integrated using a common data system. This new system will have linkages to the Early Intervention Services data system to increase the referrals of eligible children.
- 2) Increase Genetic Awareness
Educational materials and activities will be developed and implemented for consumers, health care providers, public health professionals, legislators and policy makers.
- 3) Incorporate genetics follow-up for public health programs.
Genetics content which may include education and referral for genetic counseling and evaluation will be incorporated into the newborn hearing screening program. Also, in collaboration with the chronic disease program, one model chronic disease program will be chosen to develop and implement genetics content, referral and follow-up activities into the program. This model will be evaluated for use in other chronic disease programs.
- 4) Investigate utilization of new technology for newborn metabolic screening.
A workgroup will investigate the practicality (validity, cost effectiveness, acceptability by the community, etc.) of adding new technology, such as Tandem

- Mass Spectrometry Screening, to our NBMS Program. Information from the workgroup will be presented for review by the NBMS Advisory Committee.
- 5) Ensure that Public Health Genetics Programs Have Stable and Sustainable Funding. The project staff will work to increase the knowledge and use of the State Genetics Plan to advocate for local, regional and state funding for genetics activities. The project staff will identify and publicize funding sources for genetics activities and provide technical assistance to obtain funding for other programs as time permits.

Evaluation: The evaluation will include: (1) process evaluation of the attainment of stated goals, objectives and activities within the given time frame; (2) increased integration of data and information systems related to genetics; (3) analysis of pre and post test results from educational activities; (4) analysis of evaluation forms from activity participants; and (5) tracking the use of project materials such as number of media segments generated, hits on the website, and requests to project staff for more information.

Experience to Date:

- 1) Department of Health established Newborn Metabolic Screening Program (1986), Birth Defects Program (1988), Newborn Hearing Screening Program (1990), and full time State Genetics Coordinator position (1993).
- 2) Genetics Needs Assessment completed in 1993 and State Genetics Plan completed in 1994.
- 3) The Newborn Metabolic Screening Program centralized the newborn screening laboratory services, standardize follow-up procedures, improve tracking systems, and became self sustaining (1996).
- 4) The Principal Investigator was a member of the HRSA/AAP Newborn Screening Task Force (1999)
- 5) Department of Health awarded HRSA State Genetics Planning Grant to redo genetics needs assessment and revise state genetics plan (2000).

Text of

Annotation: The Hawaii Genetic Awareness, Implementation, and Data (GeneAID) Project will integrate the information and referral systems for the Newborn Screening programs, Children with Special Health Needs Program and Early Intervention Services program. The project will increase genetics awareness in health care providers, consumers, public health professionals, and policy makers. HIGIP will also incorporate genetic content and referral for genetics services in newborn screening and other appropriate public health programs such as chronic disease.

Keywords: Hawaii, Genetics, State Genetics Coordinator, State Genetics Plan, Data Integration, Genetic Needs Assessment, Genetic Awareness, Newborn Metabolic Screening, Newborn Hearing Screening, , Birth Defects Program